

Looking after someone

Information and support for carers in **England**



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About this guide

Every day 6,000 people in the UK become carers, looking after family or friends who are older, disabled or seriously ill.



At times, caring can bring many positives and rewards. There's nothing more natural and human than helping our loved ones get the most out of life.

There's also nothing more difficult than focusing on someone else's needs without neglecting our own. Whether we're caring around the clock or balancing caring with work and family life, it can be exhausting.

The 'system' can be bewildering. The emotions can be shattering.

This guide is designed to outline your rights as a carer and the support available to you.

We have produced separate versions of this guide for carers living in Scotland, Wales and Northern Ireland because there are some differences in legislation, health and social care.

However caring affects you, we're here.



This icon means there is a Carers UK factsheet available to download for free from our website: carersuk.org/factsheets

You can find our COVID-19 guidance at carersuk.org/coronavirus

A carer's guide

Looking after someone can be tough. Here are 10 of the key challenges that caring can throw your way...



Getting the right advice and information... quickly!



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Caring can be extremely complicated, whether we're grappling with the benefits system or considering how to pay for care. Each strand is confusing but when all the strands are tangled, it can feel bewildering. Turning to an expert can help to unravel the most complex situation.

"I was on the verge of a breakdown, and my family life was almost in crisis. I contacted the Carers UK Helpline and you gave me vital information that empowered me to challenge and win my case with my council."

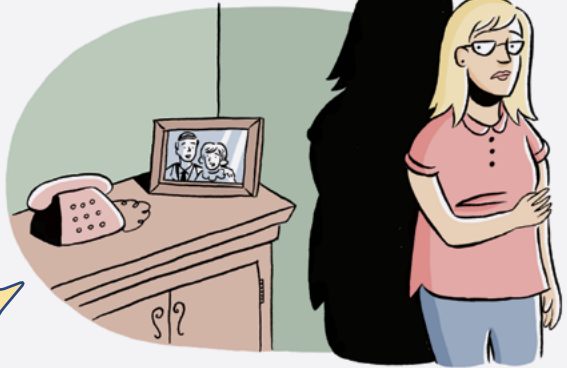


Coping with feelings of guilt

When we're looking after someone, it's important to accept that guilt is normal and that we only feel it because we care. Being able to talk to people who understand what we're going through and how we feel can help us handle our feelings of guilt better.

"After the diagnosis, I was consumed with the thought that I could have done more. Why didn't I recognise the signs? I now accept that what has happened isn't anyone's fault.

So now I don't say I feel guilty, I say I feel sad – an easier emotion to cope with."



Being assertive with professionals

Looking after someone will often involve dealing with several different professionals. When we feel a professional has not explained things clearly, does not see the whole picture or perhaps is not doing what they should do, it can be hard to speak up. However, that is exactly what we need to do. And this starts with valuing ourselves and our caring role.



"The doctors discussed his condition with me and agreed that we should implement a care plan to give Dad a dignified and pain-free death. They asked if I wanted to talk to Dad about it, and I did."

Handling difficult conversations

Even a tricky conversation with professionals can be a breeze compared to having to deal with family and friends. We may have to ask a sibling to be more supportive, remind a friend that we still exist or talk gently to a parent who doesn't accept that they can't live independently any longer. This takes courage, bags of patience and tact. Talking it through with people outside the situation can make a world of difference.

"We put off talking about mental capacity with my grandmother. Having these difficult conversations early is far preferable to leaving it too late and having other people make decisions about the future."



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Looking after our own health and wellbeing

As carers, we may have immediate needs such as taking breaks, getting sleep, eating properly or exercising. We may have longer-term needs such as building fulfilling relationships, pursuing hobbies or developing careers.

Caring always involves an element of putting our own needs aside. However it's important that we look after ourselves too, so we can keep going as carers, and because we are individuals whose needs are just as valid as those of our loved ones.



"I never took a break – I look back now and wish I had been stronger to let others help care for Mum. After years of hardly any sleep and no break, I seem to be constantly poorly and my immune system is at a low."

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Noticing when we're too stressed

Stress can alert us to potential dangers and spur us on to achieve a goal.

However, sometimes the balance tips too far and the pressure becomes so intense or persistent that we feel unable to cope.

As soon as we notice it getting too much, it's helpful to talk about how we feel rather than hoping the stress will go away.

“Sometimes stress and tiredness take their toll. One night we had a fight about nothing. At the time I didn't know what to do or where I could go for help. That's how it feels when we're under stress.”



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Making difficult decisions

There will be points when we are faced with a particularly emotional or difficult decision.

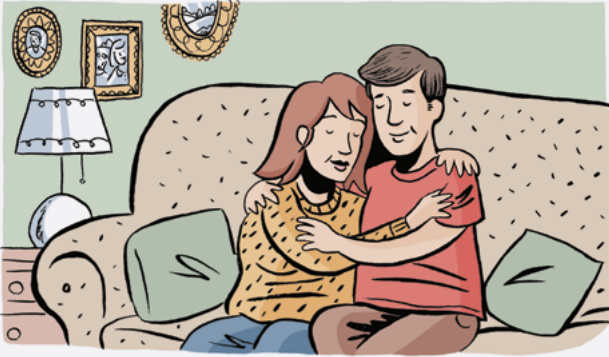
Sometimes it's a decision we have planned for, or at least held at the back of our minds. Sometimes it's completely unexpected and leaves us feeling out of control. Where we can, thinking about decisions in advance can help us keep a cool head when it comes to the crunch.

“It's better to be prepared and to do some research about different options, even if you're not sure what route you'll go down. I couldn't have selected the right care home whilst Mum was in hospital, in the middle of that stressful time.”



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Keeping relationships fulfilling



“I was suddenly juggling hospital visits, a full-time job and trying not to scream. I remember feeling I had lost all control over my life: that stroke had happened not just to Peter, but to both of us.”

Caring for our loved ones can express the best of who we are, and can take a relationship to a profound new level. It can also push us to the brink through financial, emotional and practical strain. Illness can cast aside the best-laid plans and make relationships feel utterly different. What matters most is that there’s a way for us to talk honestly and find help when we need it.

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Adapting to changing circumstances

Whether we’re looking after someone who’s recovering or whose condition is deteriorating over time, caring inevitably involves adapting to circumstances.

Sometimes it’s easy to focus on the practical details – the administration of care workers or move to the care home. Being able to stay attentive to our relationship with the person we’re caring for in the midst of all that change is far from easy.

“There were times when it seemed that Dad was at death’s door. But a couple of days later he was sitting up in bed, bright as a button. That really made the emotions difficult, constantly living on the edge.”



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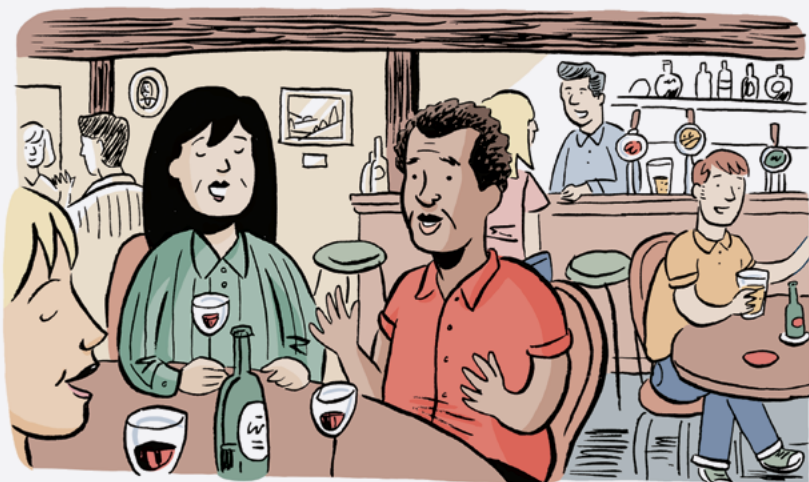
Keeping a sense of humour

Nothing relieves stress and tension better than a good laugh.

Sometimes caring can feel a bit like starring in our own sitcom, and there's no shortage of comedy material. Other times we may need a bit of help finding something to laugh about. Either way, sharing experiences with other carers is often great not just for feeling listened to and understood but for finding the humour that can keep us going.

“Dementia is no laughing matter, but humour is my way of coping.

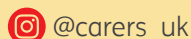
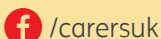
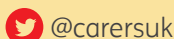
I treat most of Dad's outbursts as comedy gold for the book or the sitcom I'll never get round to writing!”



Join Carers UK for support, understanding and lasting change

However caring affects you and your family, we're here for you. By joining Carers UK, you can be part of a supportive community and a movement for change.

It's free to join us. Just visit carersuk.org/join or call 020 7378 4997.



Getting help and support



Where to start

Caring can be hard work – physically and emotionally. It's important to find out about the different ways you can get help and support with caring.

One way to get help and support is through an assessment by the local authority social services department. Both you and the person you care for can get assessments. This may result in help and support being provided to you as a carer and/or to the person you are looking after. For further information see pages 13–14.

You could decide to buy in additional help and support for the person you are looking after. One option would be to employ an individual or use a care provider such as a care agency.

If you are looking for care providers you could:

- ask the local authority if they have a list of approved care providers
- search on the Care Quality Commission website: cqc.org.uk

- search on the Housing Care services directory: housingcare.org/service

You could also find out about equipment and technology that could help. Even minor aids and adjustments could make the home safer and help someone you care for to feel more independent – see pages 22–23.

Caring inevitably means adapting to changing circumstances, so it's important to think about the future. You may need to look into different ways of managing someone's affairs, either now or for the future – see page 16.

You could find out what support is available locally. For example, there may be a carers' organisation offering services nearby. To find out what's available in your area, use our directory: carersuk.org/localsupport

Upfront is a free online tool that can help you get straight to the information you need.

Visit carersuk.org/upfront to give it a go!

Upfront



Online meetups for carers

Care for a Cuppa

Our Care for a Cuppa online chats offer the opportunity for carers to take a little break and spend some time talking to people who understand what you're going through.

Care for a Cuppa takes place online every week through Zoom.

Visit carersuk.org/cuppa

Share and Learn

We're running a series of fun and relaxed online sessions for carers where visiting speakers share tips and skills on a range of topics.

From yoga to singing, and first aid to photography, there's something for everyone.

Find out more at carersuk.org/share-and-learn

You can now watch recordings of Share and Learn sessions at:

carersuk.org/share-and-learn-videos



Carer's assessment

If you are a carer aged 18 or over, and have a need for support, you should be offered a carer's assessment by the local authority of the person you are looking after.

If you are not offered a carer's assessment, you could contact the local authority and ask for one. You can have an assessment no matter what your level of need, the amount of care you provide or your financial means. Your carer's assessment should cover:

- your caring role and how it affects your life and wellbeing
- your feelings and choices about caring
- your health
- work, study, training, leisure
- relationships, social activities and your goals
- housing
- planning for emergencies (such as carer emergency card schemes).

Following the assessment, the local authority will decide if you are eligible for support. This can be provided either to you, or to the person you are looking after to reduce the impact of caring on you.

Support could be provided by the local authority, or in the form of a direct payment.

Some examples of the kind of support you could get include driving lessons, taxi fares, a laptop or a gym membership.

Whether the local authority will pay for any support will depend on your financial situation (if the local authority is one that does charge for carer support – not all do), or the financial situation of the person you are looking after (if services are provided to them).

Even if you are not considered to be eligible for support, the local authority must provide you with information and advice on local services to prevent your needs from escalating.



Read more at [carersuk.org/
carersassessment](https://carersuk.org/carersassessment)

Assessments for children

If you are looking after a child under 18 or are a carer who is under 18, visit carersuk.org/assessments-under-18 to find out more.

Assessment for the person you care for

If the person you are looking after is an adult and appears to have a need for support, they should be offered a needs assessment by their local authority.

The person you are looking after can have an assessment no matter what their level of need or their financial means. If they are not offered a needs assessment, they (or you) could contact the local authority and ask for one. The assessment will look at their physical, mental and emotional needs. You can also be involved in the assessment as their carer (with their consent).

Following the assessment, the local authority will decide whether the person you are looking after is eligible for support. Support could be provided by the local authority, or in the form of a direct payment.

Some examples of the kind of support the person you are looking after could get include: changes to their home to make it more suitable, a care worker, a place at a day centre or a temporary stay in residential care.

Whether the local authority will pay for any support provided will depend on the financial situation of the person you are looking after. The exception is if the support is of a type that must be provided free of charge, such as aids or minor adaptations (which means adaptations up to the value of £1,000).

It may also be possible to claim certain disability-related expenses if you are contributing towards your care. Find out more at [carersuk.org/disability-related-expenses](https://www.carersuk.org/disability-related-expenses)

Even if the person you are looking after is not considered to be eligible for support, the local authority must still provide information and advice.



Find out more at [carersuk.org/needs-assessment](https://www.carersuk.org/needs-assessment)

Note: Needs assessments are for adults (18+)

If you are looking after a child under 18 who is a 'child in need', they can have a Children Act assessment from the local authority. A Children Act assessment will consider all the help that your child needs, the needs of any other children in the family and the help that you may need to care for the child.

Visit [carersuk.org/assessments-under-18](https://www.carersuk.org/assessments-under-18) for more detailed guidance.

Coming out of hospital

Deciding to care, or continue caring, for someone who is coming out of hospital can be very difficult.

It is important to remember that it is your choice whether or not to take on a caring role.

Before the person you are looking after comes home from hospital, a discharge assessment should be carried out to see whether they need any support once they are discharged.

This discharge assessment should look at whether the person you are looking after is eligible for: any intermediate or reablement care, NHS continuing healthcare or NHS-funded nursing care, other NHS services and/or community care services from the local authority.

You should also be offered a carer's assessment to see whether you, as a carer, need support once the person you are looking after is discharged.

If you are not offered a carer's assessment, you could contact the local authority of the person you are looking after and ask for one.



Find out more at carersuk.org/hospital

Our self-advocacy guide also offers tips on working with professionals. See carersuk.org/self-advocacy



The Care Quality Commission (CQC) regulates health and care services in England. This is to ensure that they are providing people with safe, effective, compassionate and high-quality care, as required by law.

By hearing about your recent experience of care, the CQC can help make care better for everyone – this is particularly important given the impact COVID-19 has had on services carers rely on.

If you have a recent experience – good or bad – please share it with them by visiting cqc.org.uk/give-feedback-on-care



Managing someone's affairs

You may want to help manage the affairs of the person you are looking after, or you may want to know how to plan for doing this in the future.

There are different ways of managing someone's affairs. Much depends on whether the person you are looking after can currently make decisions for themselves (which is called having mental capacity) or whether they are unable to make decisions for themselves (which is called lacking mental capacity).


If the person you are looking after has mental capacity but wants some help with managing their bank or building society account, they could make a **third party mandate**. This gives a specific person, such as you as their carer, authority to manage their account.

If the person you are looking after can make decisions for themselves at the moment but wants to appoint a specific person, such as you as their carer, to make certain decisions on their behalf, should the need arise in the future, they could make a **lasting power of attorney** while they are still able to do so. The person you are looking after can only make a lasting power of attorney while they have mental capacity.

There are two main types:

Power of attorney for property and financial affairs – bank accounts, paying bills, collecting benefits/pensions and selling a home for example. It can be used before the person is unable to make their own decisions, if they so wish.

Power of attorney for health and welfare. It can only be used when the person is unable to make their own decisions.

 Find out more at carersuk.org/managing-someones-affairs

MyBackUp

Our contingency planning tool could help you prepare for the unexpected. Go to: carersdigital.org/mybackup



Taking a break

Caring for someone can be a full-time job so breaks are vital for your own wellbeing and quality of life.

With the added demands of caring during the COVID-19 pandemic, you may feel particularly run down and in need of a break, especially if the respite services you formerly used are no longer operating as before.

Think about the kind of break that you need and what kind of alternative care the person you are looking after needs.

There are different options for getting alternative care (often called respite care) for the person you are looking after whilst you take a break. These include:

- getting help from the local authority social services department via assessments (see pages 13–14)

- arranging care yourself (see page 11)
- support from friends or family
- some organisations provide break services for carers or for the person being looked after (or both).

If you want to go on holiday, either alone or with the person you are looking after, there may be some help you could get towards the cost. You could see if there are any local grants or schemes to help carers with the cost of a holiday and you could have a look through the list of organisations in our *Taking a break* factsheet.

 Find out more at carersuk.org/break-factsheet

“Catch up on sleep and give yourself time to think. There is no right way to use your time, just be gentle on yourself.”

“It took years before I was able to consider respite for my daughter. Years on, I now know I need that complete break each year. I come back recharged and more able to cope.”

Looking after yourself

Caring can put a strain on your mental and physical health. It can feel as though there is very little time for you to take a breather. However, it's vital to find moments to relax and destress.

Here are some suggestions to help you look after yourself and develop your resilience.

Expand your support network

Keeping in touch with family, friends or neighbours about your circumstances may help open up more doors for support when needed. You could join other carers at one of our online meetups (page 12). If you feel you need more emotional support, you could also sign up for a series of phone calls from our Listening Support Service. See page 42 for contact details.

Need more sleep?

It may be particularly hard to get the sleep and rest you need, especially if you are helping to look after someone during the night. If you have trouble switching off, there are specially tailored apps that can help, or you may wish to speak to your GP if you're really struggling. The NHS website also has some helpful suggestions: [nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/](https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/) and see our tips here: [carersuk.org/getting-enough-sleep](https://www.carersuk.org/getting-enough-sleep)

Don't neglect your health

Eating well and making a habit of doing an exercise you enjoy are great ways to stay healthy, but it can be challenging to eat well and exercise with a busy caring role. Take a look at our Carers Active Hub for ideas and inspiration: [carersuk.org/carers-active-hub](https://www.carersuk.org/carers-active-hub).

Speak to your GP if you are concerned that your caring responsibilities are having an impact on your health so that they can offer you further advice.

Keep up your own interests

As well as doing a physical activity you enjoy, pursue any interest you can to maintain your sense of identity and keep your spirits up, even if it's only 10–15 minutes. Don't feel guilty and try to arrange extra support to help you do this if you need to – see pages 13–14 and page 17.

Jocelyn's story

Jocelyn has been caring for her daughter, Amy, and her husband, Darran, for over 30 years. They believe breaks are essential.

“ When my daughter was four, she was diagnosed with a rare genetic condition called Trichothiodystrophy. This means that she has complex needs both physically and mentally. Several years later, my husband had an accident whilst working at the steelworks which resulted in him losing an arm and leg. This was life-changing for everyone. When I look back, I just think how did we get through that? Caring is not something you plan for. Truthfully, it was tough.

Having a break away allows you to be yourself for a while and enjoy the simple pleasures in life others can take for granted, such as going for a coffee or going to the cinema. It allows you to be free. You always feel lifted afterwards and it's important to just let go.

My idea of a break is to find a quiet place where I can be on my own for a couple of hours. It might involve taking the dogs for a walk or losing myself in a book. I like to visit art galleries and maintain hobbies I had before Amy's diagnosis and



Darran's accident, such as painting and drawing. I think it's important to retain some kind of identity because you can get lost in your caring role.

It's important to take time to recharge your body and mind. If you try to give without looking after yourself, you can run on empty. I've done that in the past and became very ill.

I got to a crisis-point where I was struggling and so I contacted Carers Wales – Beth's guidance made all the difference. It paid off as I was able to have a carer's assessment which helped me tremendously. Despite her limitations, Amy's enjoying her life to the full thanks to the direct payments we've received, which makes me happy.

My advice is don't be afraid, and really try to think of it as an investment for your own mental welfare. You have rights, and you can ask for help, and how to go about getting that help.

”



See carersuk.org/break-factsheet for more information.
Or watch our film series: carersuk.org/breaks

Jennie's story

Jennie cares for her three children who have complex needs. As an Enteral Nurse Specialist, she also looks after adults and children who are tube fed and provides training for their families.

Inspiringly, she's also a parent ambassador for Wellchild and runs a local rainbow unit.

“ I'm a carer for three children. We face challenges every day which has only been made harder by the COVID-19 situation.

We have Jack who's 19 and has ADHD and Tourette's. He was also tube fed for 15 years.

My daughter, Olivia, is 17. She has Narcolepsy and Cataplexy and collapses 30+ times a day. This means that she can't go out alone. She is currently tube fed and needs full support with this.

Finley, our 11 year old, has autism and gut dysmotility so has a jejunostomy tube connected to a pump 21 hours a day and a drainage bag from a gastrostomy tube to keep his tummy empty.

These are not designed for an active child who has no fear. His pump has been in the sea; it's been on a lake when he fell out of a canoe; it's been down the stairs. He has gone down a slide and left his whole tube at the top and pulled it right out. If you turn your back, he is causing problems somewhere.



This isn't just daytime care we provide for them all. At night, we have pumps alarming or sleep paralysis to deal with. As you can imagine, we are always chasing hospital appointments or prescriptions, trying to get assessments for equipment and then playing 'Jenga' trying to fit it all in the car or house.

It's a full-time job some days, and this is then on top of our full-time jobs. I try to book time out for appointments when I need to but I do struggle sometimes; I'm sometimes tired and emotional and don't get as much sleep as I should do. Our health always seems to take a back seat to the children which I think will become a problem in years to come.

I've been lucky enough to work for Nutricia who have been supportive of my role as a carer. I have had to be off work at a moment's notice when one of my children has been admitted to hospital and my team has always stepped up and covered my visits.

An important tip I have as a carer is to find your people: people in similar situations to you. Carers UK, WellChild, and Swan UK all have parents who get it and have helped me a lot. The biggest frustration is that professionals

often assume that everyone gets Carer's Allowance for caring. They also assume we get respite. It's a surprise to learn that everything is a fight. Every other carer in the same boat as us is a hero.



Carers UK is working in partnership with Nutricia to help improve understanding about nutrition and care.



Nutricia specialises in the delivery of medical nutrition for the very young, the old and the sick. They supply high quality feeds, systems and support services to patients and healthcare professionals.

Mike's story

“ In 2012, I discovered Carers UK after being a carer for my father for more than five years. It was during this time that I was looking for organisations I could volunteer for to use my experience.

I am forever grateful to Carers UK for involving me. Being a voice for carers since then, I have never looked back because there are so many unidentified carers out there who are desperately seeking guidance and practical help. The thought of many unfound carers who are missing out on support simply because they don't consider themselves as carers, fills me up with the dedication, passion and drive to reach out, especially to those belonging to BAME and other marginalised and silent groups, such as the very young or elderly carers, as well as working 'sandwich' carers.



I have been involved as a user representative and a voice of carers with CCG, NHS Trusts, local authority, GP practices, CQC, GM Cancer, GM Mental Health and other platforms events.



Interested in volunteering?

Contact volunteering@carersuk.org for more details.

Equipment and technology

Different types of equipment, adaptations and technology could help make the home safer, your life easier and provide independence for the person you are looking after.

Equipment could be purchased privately or you might be able to get help with the cost through the NHS or through assessments from the local authority, if they decide that such equipment is necessary.

Minor adaptations (which means adaptations up to the value of £1,000) should be provided free of charge through assessments from the local authority, if they consider that the person you are looking after needs such adaptations. Adaptations that cost more than £1,000 could be paid for privately, or you could see if the person you are looking after can apply for a disabled facilities grant.

Assistive technology can help people live independently in their own homes and give you, the carer, peace of mind.

Unobtrusive monitoring devices such as sensors can be positioned throughout the home. They can detect if there is a problem, such as a gas leak or fire, and the person you look after needs assistance. Wearable technology can detect falls or locate a person if they have wandered.

There are also ways of using technology to monitor a person's health remotely through equipment they have in their home. Conditions such as asthma, heart failure, diabetes, chronic obstructive pulmonary disease (COPD), stroke and hypertension can be monitored.

Everyday technology, such as the internet or your mobile phone, can take the stress out of a whole host of tasks such as shopping and coordinating care for the person you look after, and can help them manage their own condition.

Find out more at carersuk.org/tech



Smart meters send gas and electricity readings automatically to the energy supplier. This could help give greater independence to the person you care for and could help save time and money if you are helping them manage their energy.

Smart meters come with an in-home display so you can see how much energy is being used and how much it's costing. With a smart meter you get a bill based on how much energy you used – not an estimate. This can take some of the guesswork out of balancing budgets.

Smartphone features and apps have a lot to offer. You can use your phone to scan a document if needed so that you have a back-up version to refer to on your phone for appointments, for example, or you can use the reader mode feature to research key information without interference from adverts. The medical ID setting is also worth exploring.

Connected devices – examples include smart bulbs or blinds that can be controlled remotely. This means that if the person you look after lives at a distance, you can control things like their lighting on their behalf or use smart heating controls to ensure their heating is on or off when appropriate. Voice controlled devices (such as Siri or Alexa) can also be useful for disabled or older people.

Financial support

While technology and equipment can make your life easier, costs can also add up. You may be able to get financial support to help you pay for some types of technology and equipment. For more information on financial support that may be available to you, you can contact our Helpline team by emailing advice@carersuk.org at any time.

Please note where you are from as guidance will vary by nation.

Support during tough times

The **Priority Services Register** is for anyone who is in a vulnerable situation and in need of extra support even if this is just needed on a temporary basis. All energy suppliers provide this additional support for customers who need it. It enables you to be prioritised for services, for example, if your energy supply is cut off due to an unforeseen incident.

Read more: [ofgem.gov.uk/information-consumers/energy-advice-households/getting-extra-help-priority-services-register](https://www.ofgem.gov.uk/information-consumers/energy-advice-households/getting-extra-help-priority-services-register)

Olga's story



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“ When I first heard about Carers UK's Jointly app, I was juggling full-time work with caring for my parents. I was living in London – 170 miles away from their home in Staffordshire.

It was a complicated and stressful situation. My mum has a range of conditions, including osteoporosis and arthritis. My dad had been caring for her, until 2015 when he was diagnosed with lymphoma and needed care himself.

My siblings and I tried to coordinate it between us, taking turns to travel to their home to help around the house, cook meals and take them to appointments.

Jointly was an excellent way of making sure we had all the information we needed in one place. We only had to enter the

information once and all of us had access to it. Up until then we'd been trying to coordinate everything through email, phone calls and trying to share calendars.

Each time one of us took Mum or Dad to an appointment we would make notes in Jointly. The medication list meant we all had up-to-date information to share with the GP – which was essential when Dad was prescribed aspirin, which he wasn't allowed to have whilst on his cancer drugs.

Being able to look after my parents has been really important to me. I wanted to return the care and love they gave me during my childhood. After Dad passed away in 2016, my siblings and I have continued to share the care for Mum, and Jointly helps us do that. ”

Looking after someone?

Our *jointly* app can make your life easier



Looking after someone can be complicated. Jointly helps me stay on top of things and share information easily with everyone involved in sharing the care.

Jointly makes caring less stressful and a lot more organised.

Jointly is a mobile and online app designed to keep people connected as they share care.

It includes:

- Group messaging
- Task management
- Shared calendar
- Profile and contacts pages
- Medication manager
- Notes
- Contingency planning.



Caring is easier when you do it *jointly*

jointlyapp.com

Developed by Carers UK



 **carersUK**
making life better for carers

Your finances



Getting information on benefits

There are various benefits that can offer extra support with caring. This section provides an overview of what help is available.

It is a good idea to get a benefits check to make sure you and the person you are looking after are claiming all the benefits you are entitled to. In addition, it is a good idea to get benefits advice if you or the person you are looking after have a change of circumstances. The change might affect your benefits, so it's important to make sure you make the right decision for your situation.

Although benefits can be complicated, they can increase your household income and can sometimes help protect your State Pension entitlement in the future.

The Carers UK website describes the main conditions for each benefit and we have produced factsheets which provide more detailed explanations. Find out more at carersuk.org/benefits

The Carers UK Helpline can also help with questions that you have about benefits – email advice@carersuk.org or call 0808 808 7777.

Please mention where you are from so that we can tailor our guidance.

Check here for opening hours: carersuk.org/help-and-advice/talk-to-us

You can get a personalised benefits check online. It will take about 20 minutes to complete. Visit carersuk.org/benefits-calculator

These online benefits check tools are not suitable for everyone. Special rules apply to some groups of people, for example: students, people under 18, people in permanent residential care, UK nationals who live abroad and people who are not British or Irish citizens.

“Thank you so much for taking the time to do some research for me. I have calmed down somewhat now and can look at things more objectively having read your reply.”

Carer's Allowance

If you're looking after a family member or friend, you may be entitled to Carer's Allowance.

You may be eligible for Carer's Allowance if you meet all of the following conditions:

- you look after someone who gets a qualifying disability benefit – this includes the middle or the higher rate of the care component of Disability Living Allowance (DLA), either rate of the daily living component of Personal Independence Payment (PIP), either rate of Attendance Allowance, Constant Attendance Allowance (at a certain level) and Armed Forces Independence Payment (AFIP)
- you look after that person for at least 35 hours a week
- you are aged 16 or over
- you are not in full-time education
- you don't earn over £132 a week (after deductions)
- you satisfy UK presence and residence conditions.

If you are getting certain other benefits, including a State Pension, then you might not be able to be paid Carer's Allowance at the same time.

However, it might still be useful to make a claim and receive what is called the 'underlying entitlement' to Carer's Allowance, even though you won't be paid the benefit itself. This is because this 'underlying entitlement' to Carer's Allowance can help to increase any means-tested benefits you might be getting (such as Pension Credit, Housing Benefit and Council Tax Reduction), or it could mean that you become entitled to means-tested benefits for the first time.

Claiming Carer's Allowance can sometimes have an impact on other benefits you receive, but this shouldn't put you off thinking about making a claim, as it can often increase your household income overall.

Claiming Carer's Allowance never reduces the amount of Disability Living Allowance (DLA), Personal Independence Payment (PIP), Attendance Allowance or State Pension that the person you are looking after gets. However it can sometimes affect any means-tested benefits they get.



Find out more at carersuk.org/carersallowance

When claiming, if your circumstances change, you must always notify the Carer's Allowance Unit: gov.uk/carers-allowance-report-change

Carer's Credit

Carer's Credit is a way of protecting your State Pension rights. It applies if you are looking after someone, but are not paying National Insurance contributions through paid work and are unable to claim Carer's Allowance.

You do not get paid any money if you claim Carer's Credit. However you get a National Insurance contribution credit to help protect your record (which helps to protect your entitlement to a State Pension).

If you already get Carer's Allowance, then you do not need to claim Carer's Credit as your record is already protected.

To claim Carer's Credit you need to be looking after someone for a total of 20 hours or more a week. Normally, the person you are looking after must be getting one of the following:

- the middle or the higher rate of the care component of Disability Living Allowance (DLA)
- either rate of the daily living component of Personal Independence Payment (PIP)
- either rate of Attendance Allowance
- Constant Attendance Allowance
- Armed Forces Independence Payment (AFIP).

However, if the person you are looking after doesn't get one of these benefits, you may still be able to claim Carer's Credit. When you apply, fill in the Care Certificate part of the application form and ask a health or social care professional to sign it.

Carer's Credit can also help with breaks in your caring role. You can claim Carer's Credit for any week within 12 weeks before the date you become entitled to Carer's Allowance or following the week you stop being entitled to Carer's Allowance. This is without meeting the 20-hour condition. This means you could have a break in caring for up to 12 weeks without losing your National Insurance contribution credit.



Find out more at carersuk.org/carerscredit




Disability benefits for the person you are looking after

The person you are looking after may be entitled to disability benefits to help pay for the extra costs of long-term illness or disability.

Disability benefits are not dependent on how much money the person you are looking after has, and they are not based on their National Insurance record. However, there are conditions they would have to meet in order to receive one of these.


Disability Living Allowance (DLA)

If you are looking after a child under 16 then you could claim DLA for them. DLA has a care component which may be awarded if the child needs help with personal care (such as dressing, washing or using the toilet) or supervision to make sure they are safe, because of their illness or disability. The help the child needs must be substantially more than the help needed by a child of the same age without the illness or disability. DLA also has a mobility component which may be awarded if the child needs help getting around.

 Find out more at carersuk.org/dla


Personal Independence Payment (PIP)

If you are looking after someone aged between 16 and State Pension age, then they could claim PIP. PIP has a daily living component which may be awarded if they need help with daily living activities, such as dressing, washing or using the toilet. PIP also has a mobility component which may be awarded if they need help getting around. If you are aged between 16 and State Pension age, and have such needs yourself, you could also apply.

 Find out more at carersuk.org/pip

Attendance Allowance

If you are looking after someone of State Pension age, they could claim Attendance Allowance. Attendance Allowance may be awarded if they need help with personal care (such as dressing, washing or using the toilet), or supervision to make sure they are safe. If you are of State Pension age and feel you have such needs, you may also be eligible.

 Find out more at carersuk.org/attendanceallowance

Help with Council Tax

If you're caring for someone, you may be able to get help with your Council Tax bill.

Council Tax Reduction (sometimes called Council Tax Support) is a scheme run by local authorities to help those on a low income with their Council Tax bill.

There are also a number of circumstances in which **properties can be exempt from Council Tax**. These are the ones that may be particularly relevant to you as a carer:


- if you have left the property empty and it is no longer your main residence because you are providing personal care to someone
- if the only person(s) living in the property is severely mentally impaired and receives certain benefits, and no one else could be liable to pay the Council Tax
- if the property has been left empty by someone who is now resident in a hospital, a care home or a hostel where personal care is provided.

There are sometimes **discounts you can get on the Council Tax bill**. If only one person lives in the property, a 25% discount can be applied to the bill, and if no one lives in the property, a 50% discount can be applied to the bill.

Certain people, including some carers and people with a severe mental impairment, are not counted when the council works out how many people live in a property.

In order to apply for one of these discounts, you will need to contact the local council directly. You can look up the details of your local council here: gov.uk/find-local-council

You may also be able to pay less Council Tax under the **disability reduction scheme** if your home has had work carried out on it to help you or someone else living with a disability.

 Find out more at carersuk.org/counciltax



Other financial help

There are other ways you may be able to reduce your household expenses – from getting help with energy and health costs, to applying for certain loans or grants.

Help with energy costs

There are a number of ways you can get help with energy costs:

- You could contact your supplier to see if they have any discounted tariffs you are eligible for. You may also want to shop around to see if you can find a better deal from another supplier, by using a price comparison website.
- If you have reached the qualifying age, you may be entitled to a Winter Fuel Payment to help pay winter bills – this can be between £100 and £300 depending on your circumstances.
- If you're receiving certain benefits, you may be able to get a Cold Weather Payment of £25 for each week between 1 November and 31 March in which the average temperature in your local area is at or below freezing over seven consecutive days.
- If you meet certain conditions, you could get a Warm Home Discount on your electricity bill – this can be around £140.

Find out more at carersuk.org/fuel

Help with NHS health costs

If you are getting certain benefits, you may qualify for help with NHS health costs. This includes free prescriptions, free dental treatment, free NHS eye tests and vouchers to help pay for glasses/contact lenses, as well as reimbursement of fares to hospital for treatment for you or your child. You can also claim for the fares of a companion who needs to travel with you for medical reasons.

If you are aged 60 or over, you can get free prescriptions and NHS eye tests regardless of your income.

If you aren't getting benefits that entitle you to help with NHS health costs, but you have a low income, you may be able to get help with health costs through the NHS Low Income Scheme.

Prepayment certificates for prescriptions can also reduce costs if you regularly pay for medication.

Find out more at carersuk.org/healthcosts

COVID-19 financial support

In our A-Z listing, look up 'Debt worries' for guidance on what support is available in relation to the pandemic:

carersuk.org/covid-19-a-z

Budgeting Loan

If you are claiming certain benefits, you may be able to get a Budgeting Loan to help pay for essential things like rent, furniture, clothes or funeral expenses.

The smallest amount you can borrow is £100. Budgeting Loans are interest free so you only pay back what you borrow. You normally have to repay the loan within 104 weeks.

Find out more at gov.uk/budgeting-help-benefits

Help from your local authority

Your local authority may have a welfare assistance scheme to help people in a crisis and/or those who cannot afford to buy household goods like fridges, freezers, beds etc.

You could get in touch with your local authority to see what help they can offer.

Using our local directory might be a helpful starting point:

carersuk.org/localsupport

Grants

There are sometimes grants that you may be able to apply for. You could ask a local advice centre if there are any local grants.

Turn2us is a charity that has a grants search tool. Find out more at turn2us.org.uk



Sarah's story

Sarah is a carer for her mum, Jean. They live together in Scotland. Sarah supported her mum to get a smart meter.

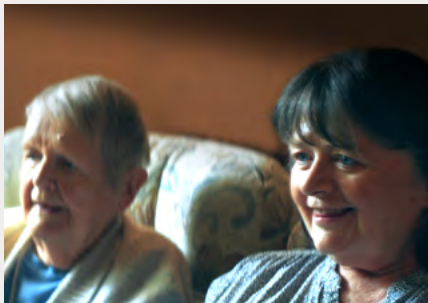


Energy prices are rising. Like Sarah, you may want to keep a closer eye on the energy usage of the person you support, making sure they are keeping warm and healthy.

Smart meters and the in-home display can help. They allow you to see how much energy is being used and how much it's costing.

“ My main memories of Mum growing up was that she encouraged us to play in natural environments, like in the glen and down in the park, and just enjoying the natural world. She was quite strict as well in many ways, especially about not wasting things. Environmentally she thought that was important.

Mum enjoys watching the birds and the wildlife in our garden, like the hedgehogs and the foxes.



She now finds it difficult to stand for too long and to make her own meals. That's where I can help out a bit. I also help with keeping track of bills for her.

Getting a smart meter has been quite useful because it helps you see in real time how much power you're using. If something's left on accidentally, you might not notice it for quite a while but you would notice it on the in-home display. It makes Mum more independent because she knows where the smart meter is so that if we've turned the heating up, she can go and have a look.

I would recommend that other people who might be caring for a relative get them. I can keep a track of the bills. It all being done helps her not worry. And I can also check that everything's OK. ”

Carers UK is working in partnership with Smart Energy GB to help carers learn more about smart meters, and how they could benefit the person that you care for. For more information visit [smartenergygb.org](https://www.smartenergygb.org)

Your work



Working carers

If you are juggling work with caring for family or friends, you are not alone – there are up to five million working carers in the UK.

There are rights you have in the workplace that might help you to combine work and care (see pages 37–38). As well as these statutory rights, you may also have additional contractual rights.

In addition to your rights at work, there might be other ways to strike a better balance, such as accessing relevant support at work (see page 39), or outside of your employment.

If you are struggling to manage work and care and are thinking of leaving work, it is important to consider the full implications this could have on your income, quality of life and future pension entitlements.

You could get a benefits check to find out what your financial situation would look like if you were to leave work or reduce your hours (see page 27).

Before deciding to give up work, it's worth seeing if you can improve your situation. See if there are any rights you have at work that could support you with your caring commitments (see pages 37–38), and check what other sources of help are available (see page 39).

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Watch our film series for useful tips on flexible working: carersuk.org/flexibleworking

You can also download the guide, *Let's talk about flexible working*: carersuk.org/flex-working-guide

Your rights in work

Without the right support, the stress and pressure of juggling work and care can lead people to leave their jobs. It's important, therefore, to find out about your rights and about any support that is available.

Your rights at work come from two sources:

- The law gives you 'statutory rights', which everyone has.
- Your contract of employment gives you 'contractual rights', which can be more generous than statutory rights.

The following information is about statutory rights. However it is always worth checking your contract of employment, staff handbook or letter of appointment to see if you have any contractual rights on top of your statutory rights.

All employees have a **right to request flexible working** after they have worked for the same employer for 26 weeks (six months), as long as they haven't already made a flexible working request within the last 12 months.

Employers can only refuse requests for certain specified reasons.

Examples of flexible working include:

- home working
- part-time working
- term-time working
- flexitime
- working compressed hours
- job sharing
- shift work.

The Equality Act 2010 provides carers with **protection from some forms of discrimination**. For example, employers and providers of goods and services must not treat carers less favourably than those without caring responsibilities.

In September 2021, the UK Government set out new proposals to make the right to request flexible working an entitlement for every employee in Britain from day one of employment.

All employees have the right to take a 'reasonable' amount of time off work to deal with an emergency or an unforeseen matter involving a dependant. This could include your partner, child or parent, or someone living with you as part of your family – others who rely on you for help in an emergency may also qualify.

The time off is unpaid unless your employer is willing to give paid time off as a contractual right.

Examples of emergency situations:

- a disruption or breakdown in care arrangements
- the death of a dependant
- if a dependant falls ill, has been assaulted or is in an accident
- to make longer-term arrangements for a dependant who is ill or injured (but not to provide long-term care yourself)
- to deal with an incident involving a child during school hours.

“I applied to reduce my working hours from five to four days a week, on flexible working grounds. It’s hard work, but does mean I can fit in appointments and care meetings on my day off.”

If you have worked for the same employer for 12 months and you are responsible for a child aged under 18, you are entitled to 18 weeks’ parental leave per child, which must be taken by the child’s 18th birthday.

This time off is unpaid unless your employer is willing to give paid time off as a contractual right.

In September 2021, the UK government also agreed that they will introduce a day one right to one-week’s unpaid leave for carers balancing a job with caring responsibilities.

Visit carersuk.org/work to read our online information.

“My employer supports me with a great deal of flexibility. When an emergency does happen, they tell me not to worry about work.”

Getting support

Telling your employer that you are a carer may not always feel like an easy step.

Ask your employer if they have a carers policy or other support that could help you as a carer, such as special leave.

Some organisations provide support such as counselling services and information for carers such as advice packs. Trade unions can also be a good source of support. You may find that your colleagues are supportive, or even in similar caring situations themselves.

As well as seeing if there is any support available to carers through your employment, you could explore the support available outside of your employment.

This could include getting a carer's assessment to see if there is any support the local authority can offer to help you balance work and care – see page 13.

This could also involve speaking to others who know what you are going through.

Visit carersuk.org/localsupport to find carers' organisations and support services available for carers in your local area.

Our online Carers UK Forum may be a good place to speak to other carers about how you are feeling – visit carersuk.org/forum

To become part of this online community, please join us as a member: carersuk.org/join



Carers UK runs Employers for Carers, providing practical advice and resources to help employers support the carers in their workforce. You could talk to your employer about joining Employers for Carers – find out more at employersforcarers.org

Scott's story

Working carer Scott Corley's daughter, Amber, has cystic fibrosis. He shares his experience of the importance of having an employer who is supportive of carers.



“ When Amber was born I saw myself as a father, but after her cystic fibrosis diagnosis a thought jumped into my head, ‘I’ll have to give up work.’ That thought petrified me and that was when I realised I was a carer as well as a father. Now Amber’s 12 years old and my wife, Louise, and I care for her together.

I work as a service improvement partner for the Financial Ombudsman Service. My wife also works part-time for the same organisation.

It’s a balancing act. At work we try to help our managers understand our situation when we think Amber’s health is deteriorating. If I say to my manager, ‘Amber has a cough’ they need to understand that’s not just a normal cough and might be the start of something

more serious, which might involve me being away from the office.

My employers are really supportive of us. We have a dedicated carers’ group in the office and I am now its co-chair. The visibility of carers in our organisation has helped other colleagues better understand the role of carers.

Being transparent about my situation with my employers has worked for me, but I know not all employers are as receptive. The support my organisation has given me as a carer makes me more committed to them.

There have been some dark moments with Amber and just knowing that I can take a paid day’s leave to be with her makes all the difference. It feels like a bit of good luck in a sea of bad luck.



The Financial Ombudsman Service has been a member of Employers for Carers since 2012.

Managed by Carers UK, Employers for Carers helps employers in the UK to support employees with caring responsibilities. This includes training, raising awareness of caring and caring issues, reviewing and ‘carer proofing’ policies and helping organisations set up staff carer networks.

Notes

Directory

There are a range of national organisations that can provide help. We've listed some of these below.

Age UK

Information and advice for the over 60s.

T 0800 678 1602

ageuk.org.uk

Alzheimer's Society

Information and advice for people with dementia and their carers.

T 0333 150 3456

alzheimers.org.uk

Care Quality Commission

The independent regulator of health and social care in England.

T 03000 61 61 61

cqc.org.uk

Carers Trust

A network of local centres providing advice, information and support to carers.

T 0300 772 9600

carers.org

Carers UK Listening Support Service

Find a supportive listening ear by signing up to a series of calls from our trained volunteers.

carersuk.org/listen

Citizens Advice

Local offices for advice/representation on benefits, debt and housing.

T 03444 111 444

citizensadvice.org.uk

Contact

Information and advice for families who care for children with a disability or special need.

T 0808 808 3555

contact.org.uk

Disabled Living Foundation

Information and advice on equipment for independent living.

T 0300 999 0004

dlf.org.uk

Independent Age

Information and advice for older people, their families and carers.

T 0800 319 6789

independentage.org

Macmillan Cancer Support

Information and advice for people with cancer, their families and carers.

T 0808 808 00 00

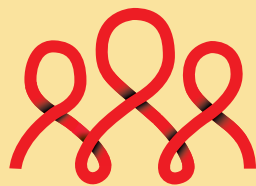
macmillan.org.uk

Carers UK Helpline

We're here for you with information, guidance and practical support every step of the way.

If you mention where you are based, we will aim to tailor our guidance for you.

E advice@carersuk.org **T** 0808 808 7777



Marie Curie

Support for people living with any terminal illness, and their families.

T 0800 090 2309

mariecurie.org.uk

Mencap

Information and advice for people with a learning disability, their families and carers.

T 0808 808 1111

mencap.org.uk

Mind

Information and advice for people affected by mental illness and their carers.

T 0300 123 3393

mind.org.uk

Relate

Counselling and support services for couples, families and young people.

T 0300 003 0396

relate.org.uk

There may be local support groups and organisations that can also provide help.

Visit carersuk.org/localsupport

Rethink Mental Illness

Information, advice and community services for people affected by severe mental illness and their carers.

T 0808 801 0525

rethink.org

Samaritans

Samaritans are open 24 hours a day, 365 days a year.

T 116 123 E jo@samaritans.org

samaritans.org

Shelter

Information and advice on housing issues.

T 0808 800 4444

shelter.org.uk

Stroke Association

Information, support and advice to help those affected by stroke.

T 0303 3033 100

stroke.org.uk

Turn2us

Information and advice on benefits and grants.

T 0808 802 2000

turn2us.org.uk



Every day 6,000 people become carers, looking after family or friends who are older, disabled or seriously ill.

However caring affects you, we're here.

For information and tailored support, contact the Carers UK Helpline:

E advice@carersuk.org

T 0808 808 7777

This guide was proudly supported by



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